Complete Summary

GUIDELINE TITLE

Managing DR-TB through patient-centred care. In: Guidelines for the programmatic management of drug-resistant tuberculosis.

BIBLIOGRAPHIC SOURCE(S)

Managing DR-TB through patient-centred care. In: World Health Organization (WHO). Guidelines for the programmatic management of drug-resistant tuberculosis. Geneva, Switzerland: World Health Organization (WHO); 2008. p. 165-70. [3 references]

GUIDELINE STATUS

This is the current release of the guideline.

COMPLETE SUMMARY CONTENT

SCOPE

DISEASE/CONDITION(S)

Drug-resistant tuberculosis (DR-TB), including:

- Multidrug-resistant tuberculosis (MDR-TB)
- Extensively drug-resistant TB (XDR-TB)

GUIDELINE CATEGORY

Management

CLINICAL SPECIALTY

Infectious Diseases

INTENDED USERS

Advanced Practice Nurses
Allied Health Personnel
Health Care Providers
Health Plans
Hospitals
Managed Care Organizations
Nurses
Patients
Physician Assistants
Physicians
Public Health Departments
Social Workers
Utilization Management

GUIDELINE OBJECTIVE(S)

- Provides guidance on how partnerships between providers and patients can be forged, in common cause
- To disseminate consistent, up-to-date recommendations for the diagnosis and management of multidrug-resistant tuberculosis in a variety of geographical, political, economic and social settings
- To enable access to comprehensive, up-to-date, technical and clinical information on the prevention and management of drug-resistant tuberculosis (DR-TB) and to encourage the implementation of known best practice
- To assist in the development of national policies to improve the diagnosis and management of DR-TB

TARGET POPULATION

Patients with drug-resistant tuberculosis (DR-TB)

INTERVENTIONS AND PRACTICES CONSIDERED

Management

1. Building patient-provider relations
2. Assessment of means
3. Provision of financial support
4. Provision of social/peer support
5. Building interpersonal skills among health care workers
6. Identification of effective counselors
7. Patient communication
8. Isolation and respect for human rights
9. Involvement of nongovernmental, community, or faith-based organizations
10. Management of treatment program

MAJOR OUTCOMES CONSIDERED

- Socioeconomic impact of drug-resistant tuberculosis (DR-TB)

- Rate of successful completion of treatment
- Patient and provider satisfaction

METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Hand-searches of Published Literature (Primary Sources)
Hand-searches of Published Literature (Secondary Sources)
Searches of Electronic Databases
Searches of Unpublished Data

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

The nominated lead author for each chapter used a limited evidence retrieval consisting of:

- Personal collection of publications and case reports
- Literatures searches using PubMed and other databases and search engines
- Existing guidelines, both from World Health Organization (WHO) and from other internationally recognized organizations
- Expert consensus during several group meetings for specific topics
- Unpublished data, for example data supplied to the Green Light Committee by their approved multidrug-resistant tuberculosis (MDR-TB) management projects

NUMBER OF SOURCE DOCUMENTS

Not stated

METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Expert Consensus
Subjective Review

RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Not applicable

METHODS USED TO ANALYZE THE EVIDENCE

Review

DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

The evidence was synthesized by each lead author, but a formal quality assessment was not used. Given the relatively small field of experts in managing drug-resistant tuberculosis, expert opinion was sought from several of the original

researchers in the field. The evidence was not formally assessed or graded and there are no formal evidence summaries.

METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

A meeting of the World Health Organization (WHO) Guidelines Steering Group, together with several WHO advisers who had contributed to the 2006 edition, took place in April 2006. It was agreed that there was an urgent need for guidance on the best response to extensively drug-resistant tuberculosis (XDR-TB), based on the emerging evidence. The group identified the chapters to be reconsidered and the gaps to be addressed in this emergency update.

Of the total 18 chapters in the original guideline document, eight have been reviewed and substantially changed in response to the emerging evidence about multidrug-resistant tuberculosis and XDR-TB (chapters 1, 4, 5, 6, 7, 10, 12 and 18). One chapter is new (Chapter 19). The remaining chapters have undergone minor revisions to ensure consistency but have not been rewritten or had any new evidence included.

There was also a decision that a full review of the Guidelines will be started after the emergency update. The WHO Guidelines Review Committee was in place by January 2008 and had already developed draft Guidance for Emergency Guidelines which was used to guide best practice in the finalization of this emergency update.

RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

COST ANALYSIS

Cost is not explicitly considered as part of the recommendations, although the realities of human resources, socioeconomic issues and health system infrastructure are taken into consideration throughout the original guideline document.

METHOD OF GUIDELINE VALIDATION

External Peer Review
Internal Peer Review

DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

The chapters were each reviewed by at least one, and usually several, members of the Guidelines Reference Group, from both within the World Health Organization (WHO) Stop tuberculosis (TB) and human immunodeficiency virus

(HIV) departments and outside external experts, as appropriate. One of the expert advisers on the Steering Group was commissioned to harmonize and review all the updated chapters. The remainder of the Steering Group also reviewed the whole document and provided extensive and detailed feedback.

The first draft of the guidelines was reviewed by the Steering Group at meeting held in February 2008. Other advisers at this meeting were Dr Malgosia Grzemska (WHO), Dr Suzanne Hill (WHO), Dr Tim Holtz (CDC, USA) and Dr Kathrin Thomas (WHO). Any outstanding issues were then resolved by e-mail to agree the final version. Other members of the group were asked to provide reviews at these later stages for particular issues.

RECOMMENDATIONS

MAJOR RECOMMENDATIONS

General Considerations

The programmatic management of multidrug-resistant tuberculosis (MDR-TB) is extremely challenging even in the best of circumstances, demanding substantial efforts from a team of health professionals and the patient to reach a successful outcome. The long duration of complicated treatment and often difficult adverse effects require a joint commitment to complete the process, and this is best practiced in an environment of mutual respect and consideration. Certain basic steps should be taken to ensure this, and some of these are made by changing attitudes, perceptions and behaviours while others may require refining existing management practices and service delivery systems.

Understanding Patient-Centred Care

All health workers involved with the management of drug-resistant TB (DR-TB) should be made familiar with the International Standards and the Patients' Charter. Copies of these documents should be made available in local languages, and staff should review their content as part of continuing education. Training materials are available upon request from the World Health Organization (WHO), the Tuberculosis Coalition for Technical Assistance and the World Care Council, and technical assistance can also be provided. An understanding of patient-centred care provides the basis to build better patient–provider relations, and can contribute to improved adherence to treatment, reduced stigmatization and better treatment outcomes. It also sends a message to the wider effective community that DR-TB can be successfully treated within a dignified framework of mutual respect, thus facilitating case-finding and community participation.

Dignity, From Day One

People suspected of having DR-TB should begin what may be a long march towards a cure in a manner to encourage their willful participation. From the first consultation or examination, the patient should be accorded the understanding of innocence, that it is not the fault of the person that bacteria are resistant to certain drugs. Offering solidarity and compassion initially, instead of reproach, will

begin the process in a "healthy" way, which the patient will remember during the many months of treatment that follow.

To grow this initial expression of respect into a sustained programmatic management tool, at the first consultation patients should be provided with a copy of the short version of the Patients' Charter in their local language. This charter outlines the rights and responsibilities for patients, and its distribution will assist the provider with educating the patient about the disease and treatment as a basis for reaching better final outcomes. It is a key element of the Stop TB Strategy under component five (empowering people with TB, and communities).

The socioeconomic impact of both the physical aspects of TB and of its long-treatment can be extremely difficult for patients and their families. At the onset of treatment, an assessment of the means and financial resources of the patient should be conducted with a view to supporting those in need of assistance. Although food packages and transport vouchers may be useful in mitigating some of the difficulties, providing a minimum revenue for all patients may be a worthy investment to ensure adherence and willful participation.

In settings where many months of isolation are mandated by the state or programme, financially supporting the patient and their family with a minimum "living-allowance" would not only be a proactive step under the patient-centred care approach and an effective incentive but also a clear sign of respect for human dignity.

Staff as Stakeholders, Patients Supporting Peers

Programmes for DR-TB control should identify a member of staff who will serve as the focal point for developing patient-centred care, and to identify a number of patients who could be initiated in ways to encourage their peers to embrace this new approach. This lays the groundwork for the development of a social network within the clinical facility, which can play an essential role in galvanizing adherence and decreasing default. Working together, a health worker and a patient can facilitate a wider participation, foster a spirit of collaboration and take an innovative step to reduce stigma. This dynamic relationship facilitates gaining further support from the community and authorities to raise the standards of care.

The human resource component specifically that of health-care workers is an important aspect of the patient-centred approach and an essential factor in achieving a favorable response to treatment. Community health workers (CHWs) should be trained appropriately in communicating and interacting "positively" with both patients and families. The attitudes and interpersonal skills of health workers are tools for better outcomes, as patients default from treatment if dissatisfied with the way they are treated as human beings, and this echoes throughout the wider affected community. Furthermore, among patients in many countries, it is commonly understood that stigma, like water, flows downward, not upwards from the bottom. Health-care workers can thus play a leading role in diminishing stigma by seeing the patient–provider relationship with an appreciation of the challenges each other faces, and viewing the process to cure DR-TB as a joint endeavour.

Providing on-site social support for patients and their families through peer counselling has shown itself to be highly effective in controlling TB in a number of communities and is a key element of scaling-up the response to human immunodeficiency virus (HIV). MDR-TB control programmes should develop a comprehensive component that identifies a cured patient ("community champion"), and provides training and employment to function as a peer supporter. This worker engages in support, treatment literacy and communicating with peers under treatment. These "champion counsellors" would follow each patient from diagnosis through to cure, and act as both "friend" and educator. From the patient's perspective, having this companion available greatly reduces the psychological burden of the long duration of treatment. As it professionalizes the role of local "MDR-TB champions", it also serves to counter the systematic stigma that many patients perceive accompanies TB. Training modules and materials for the development and implementation of peer counsellor services are becoming available through the World Care Council and the Stop TB Partnership's Working Group on MDR-TB.

Communicating "Cure"

Although implementing patient-centred high-quality care, as outlined in the International Standards, will often require resources to scale up programmatic infrastructure and services, part of the process requires simple adjustments in the attitudes and language of health-care providers. Programmes that seek to manage DR-TB should appreciate the fundamental human resistance to being controlled. Although the term "TB control" is still used by many health professionals, people with the disease are much more responsive, and more responsible if the term "TB care" is emphasized. This seemingly small change in language speaks volumes to the people who must struggle to "win" the challenge of a long and difficult treatment. The word "prevention" is also seen to be more user-friendly for families and communities, which strengthens their participation in supporting patients and the programme.

Programmes should adopt methods of "communicating with" and not "talking at" patients and their families, in a manner that builds a positive partnership towards successful treatment completion. For patients with literacy limitations, efforts should be undertaken to provide audio or visual supports, such as information by recorded cassette or graphic illustrations. Staff acting as focal points for patient-centred care and peer supporters can also play an important role as "communicators".

During all phases of care, patients should be provided with appropriate and understandable information about the disease and its treatment. An informed patient can better assist health workers in caring for patients. Peer support groups, champions and trained health workers can offer information-sharing sessions to educate patients, and for better detecting risk factors for default (e.g. understanding adverse effects) and other warning signs that can affect treatment outcome. These discussion sessions should be two-way communications, mutually deciding on interventions for problems, for example, on how to handle drug side-effects.

Forced Isolation and Respect for Human Rights

Management of DR-TB, which can be a threat to public health, must be balanced with a consideration of the human rights and dignity of the patient. Guided by the Siracusa Principles, WHO states that forcibly isolating people with DR-TB must be used only as the last possible resort when all other means have failed, and only as a temporary measure.

Health authorities and providers choosing the extreme measure of involuntary treatment should do so only if they can ensure it is done in a transparent and accountable manner. If it can be proved, through evidence-based analysis, that forced isolation is temporarily required, patients must be provided with the high-quality care that includes, among other rights, free access to second-line drugs, laboratory support including effective drug susceptibility testing (DST) and social support, and be treated with respect and dignity. Patients should be informed clearly, in their language, of the decision and its details, and of their rights and responsibilities, as outlined in the Patients' Charter, accompanied by a peer supporter and/or family member.

The fear of forced isolation without consideration of patients' dignity creates a negative perception of TB control within an affected community, discouraging people from being tested for TB testing and raising the stigma attached to the disease. If the conditions of isolation are equated with punishment, efforts to stop transmission of the disease will be made more difficult.

Certain restrictions on liberties may be determined to be necessary on a case-by-case basis, but these should not be prescribed unless clinically evidenced, and with the information communicated in a clear and understandable manner to the patient, accompanied by a peer supporter and/or a family member. Independent monitoring should be welcomed by the programme to reassure families and the community that the human rights of the person are being respected. In the extreme case of XDR-TB, where cure is no longer a possibility, extra steps should be taken by programmes to ensure that palliative care is extremely patient-centred and extra measures of social support are provided to patients and their families. Although infection control remains essential and isolation may be needed, facilitating additional compassionate human contact permits the patient and his or her family the dignity to better deal with the reality. For more information on human and patients' rights, see Annex 4 of the original guideline document.

Civil Society

The involvement of civil society, such as patient support groups, nongovernmental organizations, community or faith-based organizations, in various aspects of the programmatic management of DR-TB is strongly recommended. These organizations can assist the programme through diverse but important actions, including providing social support services, case-finding, prevention campaigns and advocating for greater resources for local services. DR-TB is a problem for the affected community, and welcoming the participation and building working relations with civil society organizations not only brings new resources to confront the problem but also can serve as a dynamic link between patient and care provider (also see the National Guideline Clearinghouse [NGC] summary of the WHO guideline, Treatment delivery and community-based DR-TB support).

Conclusion

Successful management of DR-TB requires putting the patient at the centre of a comprehensive programme of care that allows patients to exercise their rights. This, in turn, enables patients to fulfill their responsibilities and assist in the treatment success. The process of adopting the patient-centred care approach is essential both for good programmatic management practices and for scaling up the response to the growing threat of DR-TB.

CLINICAL ALGORITHM(S)

None provided

EVIDENCE SUPPORTING THE RECOMMENDATIONS

TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of supporting evidence is not specifically stated for each recommendation.

BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

POTENTIAL BENEFITS

Partnerships between providers and patients facilitate a mutual collaboration to achieve cure with dignity.

POTENTIAL HARMS

Not stated

QUALIFYING STATEMENTS

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- The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted lines on maps represent approximate border lines for which there may not yet be full agreement.
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IMPLEMENTATION OF THE GUIDELINE

DESCRIPTION OF IMPLEMENTATION STRATEGY

An implementation strategy was not provided.

IMPLEMENTATION TOOLS

Chart Documentation/Checklists/Forms
Foreign Language Translations

For information about availability, see the "Availability of Companion Documents" and "Patient Resources" fields below.

INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

IOM CARE NEED

Getting Better
Living with Illness

IOM DOMAIN

Effectiveness
Patient-centeredness

IDENTIFYING INFORMATION AND AVAILABILITY

BIBLIOGRAPHIC SOURCE(S)

Managing DR-TB through patient-centred care. In: World Health Organization (WHO). Guidelines for the programmatic management of drug-resistant tuberculosis. Geneva, Switzerland: World Health Organization (WHO); 2008. p. 165-70. [3 references]

ADAPTATION

Not applicable: The guideline was not adapted from another source.

DATE RELEASED

2008

GUIDELINE DEVELOPER(S)

World Health Organization - International Agency

SOURCE(S) OF FUNDING

UK Department for International Development
United States Agency for International Development

GUIDELINE COMMITTEE

Not stated

COMPOSITION OF GROUP THAT AUTHORED THE GUIDELINE

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Disease, Paris, France; Francis Varaine, Médecins Sans Frontières, France; Marco Vitoria, WHO HIV Department, Geneva, Switzerland; Fraser Wares, WHO Regional Office for South-East Asia, New Delhi; Karin Weyer, WHO Stop TB Department, Geneva, Switzerland; Abigail Wright, WHO Stop TB Department, Geneva, Switzerland; Matteo Zignol, WHO Stop TB Department, Geneva, Switzerland

FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

All of the above contributors completed a WHO Declaration of Interest form.

The following interests were declared:

Case Gordon declared that he is an unpaid advocate for patients with anti-TB drug resistance and for improved access to high-quality care. He declared that he has himself survived XDR-TB.

Tim Holtz declared that he is an unpaid technical adviser and member of the Scientific Advisory Board of a manufacturer of anti-TB products, to advise on the development of a new anti-TB compound that will be tested in clinical trials of MDR-TB regimens.

Salmaan Keshavjee declared that his employer received funding from a foundation associated with a manufacturer of anti-TB products to support the research and training unit that he is heading.

Carole Mitnick declared that she is serving as a paid member of the Scientific Advisory Board of a manufacturer of anti-TB products, to advise on the development of a new anti-TB compound that will be tested in clinical trials of MDR-TB regimens.

Michael Rich declared that his employer received funding from a manufacturer of anti-TB products, in support of his salary.

GUIDELINE STATUS

This is the current release of the guideline.

GUIDELINE AVAILABILITY

Electronic copies: Available in English, Chinese, and French in Portable Document Format (PDF) from the World Health Organization Web site.

Print copies: Available from the WHO Press, World Health Organization, 20 Avenue Appia, 1211 Geneva 27, Switzerland; Phone: +41 22 791 3264; Fax: +41 22 791 4857; E-mail: bookorders@who.int.

AVAILABILITY OF COMPANION DOCUMENTS

The following is available:

- Executive summary. Guidelines for the programmatic management of drug-resistant tuberculosis. Geneva, Switzerland: World Health Organization (WHO); 2008. p. xi-xvi. Electronic copies: Available in Portable Document Format (PDF) from the World Health Organization Web site.

Print copies: Available from the WHO Press, World Health Organization, 20 Avenue Appia, 1211 Geneva 27, Switzerland; Phone: +41 22 791 3264; Fax: +41 22 791 4857; E-mail: bookorders@who.int.

In addition, various forms, registers, and reports are available in the appendices of the original guideline document.

PATIENT RESOURCES

None available

NGC STATUS

This NGC summary was completed by ECRI Institute on September 4, 2009. The information was verified by the guideline developer on December 11, 2009.

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